

DIAGNOSIS

HIV voluntary counselling and testing for African communities in London: learning from experiences in Kenya

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Objectives: To explore the feasibility and acceptability of translating a successful voluntary counselling and testing (VCT) service model from Kenya to African communities in London.

Methods: Qualitative study with focus group discussions and a structured workshop with key informants. Five focus group discussions were conducted in London with 42 participants from 14 African countries between August 2006 and January 2007. A workshop was held with 28 key informants. Transcripts from the group discussions and workshop were analysed for recurrent themes.

Results: Participants indicated that a community-based HIV VCT service would be acceptable to African communities in London, but also identified barriers to uptake: HIV-related stigma, concerns about confidentiality, and doubts about the ability of community-based services to maintain professional standards of care. Workshop participants highlighted three key requirements to ensure feasibility: (a) efficient referrals to sexual health services for the newly diagnosed; (b) a locally appropriate testing algorithm and quality assurance scheme; (c) a training programme for VCT counsellors.

Conclusions: Offering community-based VCT with rapid HIV tests appears feasible within a UK context and acceptable to African communities in London, provided that clients' confidentiality is ensured and appropriate support is given to the newly diagnosed. However, the persistence of concerns related to HIV-related stigma among African communities suggests that routine opt-out testing in healthcare settings may also constitute an effective approach to reducing the proportion of late diagnoses in this group. HIV service models and programmes from Africa constitute a valuable knowledge base for innovative interventions in other settings, including developed countries.

The global HIV epidemic continues to impact adversely on African communities in the UK. In 2005, nearly two-thirds of all new HIV diagnoses in Britain were among black and minority ethnic people, the majority of whom were black Africans. In addition, one quarter of the estimated 20 000 UK residents living with undiagnosed HIV infection are thought to be men and women born in Africa.¹ African migrants in the UK suffer a disproportionate burden of HIV-related illness and death because of late diagnosis; many test late because they do not perceive themselves to be at risk of HIV, or because they fear stigmatisation and deportation.^{2–5} New initiatives are urgently needed to increase the uptake of HIV counselling and testing in this group in order to ensure timely access to care and reductions in onward HIV transmission.

Several strategies are available to achieve this goal. In the first instance, it is necessary to ensure that opt-out HIV testing is carried out in sexual health clinics and that primary care providers consistently offer testing to at-risk patients.^{6–8} HIV testing should also be considered in all healthcare settings for patients with identifiable risk or symptoms of HIV infection.^{9–10} Finally, testing could be made more accessible to hard-to-reach groups such as recent migrants by expanding HIV voluntary counselling and testing (VCT) services in the community; locating VCT services in African community-based organisations, for example, could allow staff to engage with migrants who do not access mainstream health services.^{11–12}

The expansion of community-based VCT services in the UK could be facilitated through translational research. Examples of innovative service models potentially adaptable to the UK can be found among VCT programmes from East and Southern Africa. In this study, we considered the acceptability and feasibility of adapting a VCT model developed by a Kenya-based organisation, Liverpool VCT, Care and Treatment (henceforth

LVCT), for use in the UK. LVCT started in 1998 as a collaboration between the Liverpool School of Tropical Medicine, the Kenya National AIDS Control Programme and the Kenya Medical Research Institute. With funding from the UK Department for International Development, the partners carried out operational research to develop and test new approaches to VCT in Kenya. LVCT became an independent Kenyan non-government organisation in 2002, and is now the largest non-government provider of VCT services in Kenya.¹³ In the Kenyan context, VCT is a one-stop, confidential intervention aimed at asymptomatic people wishing to know their serostatus.¹⁴ Trained counsellors undertake pre- and post-test counselling and perform two parallel rapid HIV tests within a 1-h session.^{15–16} This ensures that over 99% of clients leave knowing their HIV status. VCT is either integrated into healthcare services or delivered in community settings by trained non-healthcare workers. LVCT currently implements services in stand-alone Kenyan VCT sites and gives technical assistance to partners running their own centres.¹⁷ The non-government organisation was chosen as the partner for this research because of its experience in assisting organisations in East Africa in setting up VCT services. Our study aimed to determine whether the service model implemented by LVCT would be acceptable to African communities in London and feasible in the context of NHS clinical governance.

METHODS

We conducted a qualitative study using focus group discussions and participatory methods.

Abbreviations: CBO, community-based organisation; LVCT, Liverpool VCT, Care and Treatment; VCT, voluntary counselling and testing

Table 1 Characteristics of participants in focus group discussions

Group	No of participants	Gender	Country of origin
Mixed (men and women)	11	7 female, 4 male	Burundi (1), Kenya (1), Nigeria (3), Uganda (3), Rwanda (1), Zambia (1), UK/Ghana (1)
People living with HIV	11	7 female, 4 male	Uganda (5), Rwanda (2), Zimbabwe (2), Zambia (2)
Young people	8	5 female, 3 male	Ghana (1), Nigeria (1), Uganda (1), Zimbabwe (3), UK/Malawi (2)
Women's group	6	All female	South Africa (1), Kenya (1), Uganda (2), Zimbabwe (2)
Francophone group	6	1 male, 5 female	Burundi (1), Democratic Republic of Congo (3), Senegal (1), Ivory Coast (1)

Participants and recruitment

Forty-two respondents from 14 African countries agreed to take part in focus group discussions (table 1). Participants were invited to join the study through African community-based organisations (CBOs) and community venues. In order to explore a range of perspectives from across London's African communities, we carried out purposive sampling of young people aged 18–29, people living with HIV, and women. All participants gave written consent before the group discussions. At least 15 participants were involved with HIV organisations in London.

A further 28 key informants identified through community, academic and clinical networks were invited to participate in a workshop to examine requirements for the translation of the VCT model. Workshop participants included members of African CBOs, staff working in clinical HIV services, experts in evaluation, virology and counselling, as well as staff from LVCT. University College London's research ethics committee approved the study.

Structure and analysis

Using focus group discussions, participants were invited to explore the opportunities and challenges in setting up community-based VCT services in London. All discussions were recorded and transcribed verbatim, except in the francophone group, where notes were taken and incorporated into the analysis. Three researchers coded and analysed the data independently for recurrent themes using a Framework approach.¹⁸ A workshop was held with key informants in

November 2006 after analysis of the preliminary findings from the focus group discussions.

The LVCT model and qualitative findings were presented to workshop participants, who then discussed necessary adaptations to the VCT model. We recorded these discussions, then transcribed and analysed the participants' contributions. Throughout the focus groups and workshop, the model was described as "Kenyan" in order to acknowledge its historical and geographical specificity; although LVCT was set up as a Kenya-UK collaboration, it is now an independent non-government organisation and its services have been shaped by the Kenyan epidemic.

RESULTS

Acceptability of a Kenyan-style VCT service to UK African communities

Overall, most participants felt that community-based HIV VCT would be acceptable to African communities in London, provided that steps were taken to protect clients' confidentiality and support the newly diagnosed. Participants identified several positive aspects to the service (box 1). These included the benefits of receiving HIV test results promptly through the use of rapid tests, making testing more accessible by bringing it "into the community", receiving quality counselling, increasing community ownership of HIV prevention initiatives, and employing people living with HIV.

However, participants also identified three barriers to acceptability: (a) fear of HIV-related stigma within UK African communities; (b) anxiety about breaches of confidentiality; (c) concerns about the potential lack of professionalism within the service.

Most participants thought that translating the LVCT model for London would be challenging because of perceived

Box 1: Perceived benefits of the service

Fast results and accessibility

"My friends have told me that the reason that they haven't gone for a test is because the test results takes too long. I think the advantage with this service is that in 15 minutes you know your results. I do not think it matters where the service is, people will use it."

Female participant (UK/Ghana), young people's group

"No one actually has the guts to take it from the hospitals and take it into the community, so it has become a taboo. So you have to find ways of breaking that taboo..."

Female participant (Zimbabwe), young people's group

Community ownership

"I wasn't sure when we started [the discussion], but now I think this would be a great, especially if it is owned by Africans and positive people can be employed through it and share their knowledge."

Female participant (South Africa), women's group

Box 2: HIV stigma in Kenya and the UK

"In Kenya it's [VCT] for the general population where... 30%, 25% of the population are HIV positive, and even if there is still a lot of stigma, almost everyone knows somebody who is HIV positive [...] and when you just transfer that here, African communities, ... there is something that says we're being targeted, 'we're the one's that have the virus'. Why not make it community, but community to everyone?"

Female participant (Zambia), mixed group

"I happened to mention to this friend of mine 'oh, I'm going for an HIV test'... and she said 'well why do you want to know?'. You know, as if I was stupid to talk about having an HIV test. Well you know, it's not about you, but actually I'm stigmatised with HIV."

Female participant (South Africa), women's group

Box 3: Targeting Africans

"If you target Africans only, they just feel targeted. Maybe they say, they think I am carrying it. But if it is targeting everyone, then that is better. And also we say we will be targeting African communities, but many Africans don't have that feeling of belonging to a 'community'. Which community are you talking about? They never felt part of a community so it's not their problem."

Female participant (Burundi), mixed group

differences in levels of HIV stigma between African and European settings. Many argued that black Africans face stronger HIV stigma in the UK than in parts of eastern and southern Africa, where media and educational campaigns have increased HIV awareness, and where people living with HIV are more visible (box 2). Participants also highlighted that HIV stigma among UK African communities is compounded by racism and suspicions of health tourism among the wider community. Indeed, some participants feared that targeting black Africans for VCT would reinforce existing discrimination towards Africans and further deter people from finding out their status.

Participants specifically debated the pros and cons of having a VCT service targeting African communities in London (box 3). Although some thought that an "African-owned" VCT service would increase community involvement in HIV prevention and care, several also felt that African communities in London were both too heterogeneous and too constrained by stigma to endorse a targeted service. Some advocated routine testing as a destigmatising intervention, citing the example of antenatal care screening in the UK.

The second concern voiced by participants focused on potential breaches of confidentiality within community-based settings. Some feared that people from their community would see them accessing VCT, or that staff would disclose clients' status to others outside the service (box 4). Participants also thought that community-based centres would quickly become identified as "testing venues", and that this would deter clients afraid of being seen by others from their community.

Finally, participants were unsure about the ability of trained community-based VCT staff to maintain professional standards, ensure the quality of counselling, and give appropriate support to those testing positive (box 5). They discussed the appropriateness of employing non-healthcare workers to run

Box 4: Lack of confidentiality within the community

"I am an African, and I still go back to Africa, and the fear of someone back home knowing what my status is..."

Male participant (Uganda), positive group

"People's biggest fear is their result being known in their particular community, (...) the fear of 'do they know my auntie, do they know my...' even if they are supposed to be confidential, that for me would be the biggest concern."

Female participant (Zambia), mixed group

"I think going to the GUM clinic one can feel quite anonymous whereas if you go to a community-based service someone from the community might recognise you and there is always the danger that they might tell someone else."

Male participant (Sierra Leone), young people's group

community-based VCT services; older participants and those living with HIV generally felt this was a good idea, whereas others thought it would impact on the quality of counselling and jeopardise efficient referrals to sexual health services.

Participants identified several ways of making a community-based VCT service more acceptable. Firstly, all groups suggested carrying out intensive community sensitisation in churches, schools and African social venues before opening the VCT service (box 6). The importance of community mobilisation was also emphasised to us by staff from LVCT Kenya when they recalled the early days of their service (A Njeri, personal communication, 2 March 2007). Secondly, participants advised the research team to draw on the experience of local African CBOs in order to promote and run the service. They also suggested alternative VCT models, such as mobile VCT, or offering other general health checks along with HIV testing. Finally, a consensus emerged across most groups that people living with HIV should be involved in VCT as counsellors and community mobilisers (box 7).

Feasibility

Adapting the LVCT model for the UK raises several challenges in relation to service delivery. Workshop participants identified three specific requirements for a London community-based VCT service: (1) efficient referrals to sexual health services; (2) a testing algorithm and quality assurance scheme for counselling and testing; (3) training guidelines for VCT counsellors.

Referrals

One of the biggest concerns for participants in this study was to ensure support to the newly diagnosed and fast referrals to HIV services. Whereas many Kenyan VCT sites provide treatment and support, community-based VCT services in the UK must refer clients to sexual health services for follow-up care. Participants in our study feared that poorly managed referrals would leave clients distressed and unsupported. The main recommendation put forward to improve referrals was to involve staff from sexual health clinics in the VCT service as "on call" liaison staff.

Testing and quality control

In the LVCT model, two rapid HIV tests are used to determine a client's serostatus. In the UK, however, a rapid HIV test result must be confirmed with a laboratory-based ELISA.¹⁹ Community-based VCT should therefore involve a single rapid HIV screening test, with a confirmatory test in sexual health services in case of a reactive result.⁶ Quality control should be conducted in a reference laboratory linked to a sexual health clinic. A local point of care test service committee would then set up a process for quality control and ensure that counsellors are trained and certified in the use of rapid HIV tests.^{19 20}

In the UK, services offering rapid HIV tests require clinical pathology accreditation. As discussed above, the clinical pathology accreditation does not approve of non-clinical staff interpreting test results, and community-based VCT services currently have to employ healthcare workers.¹⁹ The possibility of training non-healthcare workers to offer testing in African CBOs should, however, be explored; the recent rollout of rapid HIV tests in US CBOs serving high-risk populations and the experience of African VCT organisations have demonstrated that trained non-clinical staff are able to offer high-quality VCT services.^{14 21}

Training VCT counsellors

In the UK, restrictions around allowing non-clinical staff to carry out testing means that current community-based VCT sites must employ sexual health clinic staff. Although

Box 5: Importance of care pathways

"I think a major challenge will be the follow-up. Supposing the test comes out positive... Because the trauma suffered when you are HIV positive, what will happen? After you have tested in a community setting, what kind of follow-up will be there?"
Male respondent (Uganda), positive group

participants saw benefits to this approach, they also felt that allowing trained non-clinical staff to carry out testing would be appropriate as long as referrals were efficiently managed. VCT guidelines and training programmes designed by LVCT and the Kenyan National HIV Taskforce could be adapted for other settings, including the UK.¹⁶⁻²² The LVCT training programme would adequately meet the knowledge and skills requirements needed to deliver pre- and post-test counselling as recommended by the British HIV Association.⁶⁻²³ Our workshop participants also argued that specific training should be given to UK VCT counsellors on several issues: (1) dealing with questions about immigration status and entitlement to HIV treatment; (2) discussing prevention of mother-to-child transmission; and (3) supporting VCT counsellors living with HIV.

DISCUSSION

Most participants in this study felt that a community-based HIV VCT service would be acceptable and feasible in partnership with NHS services if steps were taken to ensure professionalism and confidentiality. The concerns discussed by our participants are not unique to African communities; they were also discussed among men who have sex with men in previous studies of community-based VCT.²⁴⁻²⁵ Our study had two main limitations: (1) the small number of participants and the fact that most resided in London, although appropriate for an exploratory study, may have compromised the generalisability of our findings; (2) fewer men than women participated, and African men's views may thus be under-represented.

The implications of our findings for future research are fourfold. Firstly, further studies should pilot and evaluate community-based HIV VCT in partnership with African communities in London. Evaluations must document clients' self-perceived risk and previous testing practices in order to determine whether community-based VCT sites attract people who do not attend mainstream sexual health services. There is a lack of clarity about the efficacy of VCT as a prevention intervention, and studies should therefore monitor the impact of pre- and post-test counselling in reducing sexual risk-taking in positive and negative clients.²⁶ Secondly, UK regulatory bodies should consider developing training guidelines for non-healthcare workers wishing to carry out HIV counselling and testing, while carefully educating target audiences to ensure confidence in the quality of testing. Seconding staff from sexual health clinics to community-based VCT services may not be cost-effective or necessary if VCT can be performed by other trained staff. Thirdly, community-based services alone may not succeed in overcoming the persistent stigma that surrounds HIV testing among African communities in the UK. One way to address this problem is to ensure that sexual health services continue to be promoted and delivered to African migrants in culturally appropriate ways. Another is to consider routine, opt-out HIV testing within appropriate healthcare settings in areas of high HIV prevalence. This approach is currently advocated by the US Center for Disease Control, but further UK research is needed to determine the local acceptability and cost-effectiveness of this strategy.²⁷ Finally, this study of a south-to-north

Box 6: Increasing acceptability

Community mobilisation

"It is not out there in my college, you know, that you could see signs, that there is counselling over there or that kind of stuff. They do not know anything about it. If you can get the counsellors out of their offices to go around and talk about the work, it would help. (...)"
Female participant (Zimbabwe), young people's group

Box 7: Involving people living with HIV

"In a way I would say you [as a person living with HIV] could become counsellors, because you have the experience, you are now the living example. You have more experience than anybody who comes in!"
"Most of the HIV positive people who are living here are struggling. They are struggling to work. And this is work that we can do!"
Male & female participants (Uganda & Zambia), positive group

translation initiative demonstrates the potential to learn from African service providers. Effective and innovative HIV interventions from developing countries are seldom translated and evaluated for other contexts, despite the benefits that they could bring to those infected or at risk of HIV.²⁸ Learning from effective HIV service models in developing countries is an opportunity to build equitable partnerships through translational research.

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CONTRIBUTORS

JI and MT had the original idea for this study. All authors contributed to planning the data collection and organising the workshop. WSS and AP carried out the focus group discussions. WSS, AP and IF collected and analysed the data. AP wrote the first draft of the paper and all authors contributed to further revisions.

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Key messages

- A community-based HIV VCT service modelled on a Kenyan example appears to be acceptable to African communities in London, with local adaptations focusing on protecting clients' confidentiality and ensuring professionalism during counselling, testing and referrals.
- As stigma remains a significant barrier to HIV testing among African communities in the UK, strategies such as routine opt-out testing in healthcare settings should also be considered.

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